

Testimony for Senate Bill 162
Monday, January 29, 2007
Helena, MT

My name is Debra Donovan. I am the Director of Program Services for the Montana Chapter of the March of Dimes Foundation.

I am here today representing the March of Dimes and its mission to improve the health of babies by preventing birth defects, premature birth and infant mortality. March of Dimes strongly supports Senate Bill 162 to expand newborn screening in Montana. Senate Bill 162 is very important in order to detect early in an infant's life, 28 disorders that may cause life threatening and debilitating conditions. Science has enabled the medical profession to identify through a blood screening which babies need to be treated to save their lives or limit the disabilities that they may have.

I was new to the March of Dimes early last year and had the opportunity after being on the job only 3 days to participate in the Task Force to study the issue of expanded newborn screening. In a room with the most informed, intelligent and public policy dedicated professionals, it became very apparent to me that expanding our current newborn screening panel is the only community and public health-conscious decision that could be made.

At times some of the language that these medical professionals used (that many times had words with 16 syllables, I swear), was more than I could comprehend, but the message was very clear: **screening for the 28 disorders and hearing can help to prevent mental retardation, severe physical disabilities and even death for children born with these conditions.**

The problem is that each state or region in the United States designs and operates its own newborn screening program, and, unfortunately, these programs can vary widely in the number and type of conditions for which they screen. As you can see on the graph with all fifty states represented, Montana is among only 7 states that tests for 10 or less. In fact we are at the very bottom of the list. How can we be the poorest at providing a healthy chance for newborn babies when most of us believe that Montana is truly the best place to live and raise our families? Currently, our state requires tests

for only 6 metabolic conditions plus hearing. A baby who is born just across the border in Wyoming will be tested for all 29 disorders and will have a chance to a productive life if the disorder is diagnosed and treatment was to begin early. Babies born in our neighboring states of Idaho, North Dakota, and South Dakota also get screened for the majority of the disorders in the core panel. That's not the case in Montana. This is not acceptable to the families in our state who may be unaware of the tests available but not required by our state. It should be a privilege to be born in the state of Montana, not a burden.

The March of Dimes support the recommendations made by the experts to require newborns to undergo the full panel of 29 genetic and metabolic tests recommended by the American College of Medical Genetics and endorsed by the American Academy of Pediatrics and the March of Dimes. Senate Bill 162 will also establish a program of comprehensive follow-up services, including education and counseling, for newborns and parents of newborns identified with disorders

On behalf of the March of Dimes, thank you for the opportunity to voice our strong support for Senate Bill 162 which would allow the state of Montana to expand newborn screening to save lives.